

Title: IUPUI Center for Cancer Population Analytics and Patient-Centered Informatics

Authors: David A. Haggstrom, MD, MAS¹⁻³, Josette Jones, PhD⁴, Layla Baker, MBChB, MPH, CCRP³

Affiliations: ¹VA Health Services Research & Development Center for Health Information and Communication, Roudebush VAMC; ²Division of General Internal Medicine and Geriatrics, Department of Medicine, Indiana University School of Medicine; ³IU Center for Health Services and Outcomes Research, Regenstrief Institute, Inc.; ⁴IUPUI School of Informatics

Abstract:

More than 30,000 Indiana residents are diagnosed with cancer each year. Cancer is the second leading cause of death in the state, claiming more than 12,000 lives annually. More than \$1 billion was spent in Indiana on direct costs of treating the cancer population in 2003. Indirect costs to cancer patients and their families are also of great importance. Cancer care coordination has the potential to reduce costs and improve quality in cancer care delivery. Coordination may occur both among (1) multiple cancer care providers caring for populations of cancer patients, and (2) between providers and individual patients with cancer

The IUPUI Center for Cancer Population Analytics and Patient-Centered Informatics was established in 2013. The center's mission is to develop team science that combines innovative health information technologies with rigorous health services research methods in order to create knowledge that will have an impact upon the health and health care of patients and populations with cancer in the state of Indiana and the U.S. The center's goals are (1) to build collaborative, multidisciplinary scientific teams to create national leaders in the state of Indiana in the fields of cancer health services research and informatics, and (2) to perform top-tier national cancer health services research and "big data" analytics to improve the quality, efficiency, coordination, and outcomes of cancer care

The Center Cores: To build our research portfolio, we have the following 2 main cores of activity:

I. Cancer Population Analytics Core: Data sources from multiple health care organizations throughout central Indiana are being joined together to answer important clinical/epidemiologic questions regarding the quality of cancer care, and design population-based, system interventions to improve the lives of Indiana cancer patients. Further support has been leveraged for this work, namely, the IU Cancer Center has provided a pilot grant to link the Indiana state cancer registry with data from the Regenstrief Institute's Indiana Network for Patient Care in order to study the utilization of high-cost imaging among cancer survivors. Furthermore, support from a Regenstrief/Merck collaboration will facilitate assessment of the quality of the data linkage at the level of both the patient and cancer case.

II. Cancer Patient-Centered Informatics Core: Multiple platforms are being leveraged to develop and test patient-centered technologies to enable individuals to track health care received and communicate with providers. Utilizing OpenMRS, a personal health record (PHR) module was created for colorectal cancer patients including treatment summary information, evidence-based decision support regarding surveillance, and online communication tools. Additional development is being focused upon updating the user interface, creating patient social networks, and providing tools to support patient well-being. Support has also been obtained from the Walther Cancer Foundation to collect information about patient symptoms and from the Regenstrief/Merck collaboration to collect patient-reported outcome measures. Finally, an NIH proposal has been developed for the SURvivorship Care Plan-PERsonal Health Record Intervention Trial (SUPER-IT), a randomized controlled trial designed to test the effect of this new technology upon both the quality of care received and patient-centered outcomes.